



Person-Directed Dementia Care

Part 1: Introduction

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Person-Directed Care Defined

- Returns decision making and choices to the person.
- Enhances the primary caregiver's capacity to engage with the person and respond to needs.
- Establishes a home-like environment.



Person-Directed Care Defined

- Involves making “culture changes” in:
 - Care Practices
 - Workplace Practices
 - The Environment



Person-Directed Care and People with Dementia

■ Evidence Based Practice Person-Directed Care:

- Eden Alternative
- Pioneer Network
- Wellspring
- “Almost Home” PBS Documentary
- LaVrene Norton, ActionPact (learning circles)
- Individual State Initiatives Through CMS



Person-Directed Care and People with Dementia

- **Evidence based practice has also been called Person Centered Care:**
 - Tom Kitwood and the Bradford Dementia Group, England. Indicators of well-being, ill-being, philosophy.
 - Jane Verity, Dementia Care Australia. Rekindling the Spark of Life Clubs.
 - Luther Manor Adult Day Services and WI Adult Day Services Association.



Old vs. New View of Dementia Care

■ Old View of Dementia Care

Medications are aimed at alleviating behavioral symptoms and improving memory.

Those with dementia are significantly different than the rest of us because of their "organic mental disorder."

Doctors possess the most reliable and relevant knowledge.

■ New View of Dementia Care

We are looking for means to prevent, delay, or slow decline through medical and psychosocial interventions.

Those who have dementia are equal members of the human race. All persons are damaged in some way. This should be reflected in our practice.

Skilled and insightful practitioners possess the most reliable and relevant knowledge.



Old vs. New View of Dementia Care

■ Old View of Dementia Care

It is important to have a clear and accurate understanding of a person's impairment in order to chart decline over time.

"Problem Behaviors" are triggered by brain pathology and need to be managed quickly and efficiently, probably with medications.

There is not much we can do positively for a person with dementia until we have medical breakthroughs. Science will provide definitive answers.

■ New View of Dementia Care

It is important to have a clear and accurate understanding of a person's background, abilities, tastes, interests, values and spirituality.

Behaviors should be viewed, primarily as attempts at communication, related to unmet needs. The caregiver needs to seek the meaning of the communication and to address the need.

There is a great deal we can do through human insight and skill.



Person-Centered Care

- Recognizes and honors the person despite the level of cognitive impairment (a disease of certain parts of the brain.)

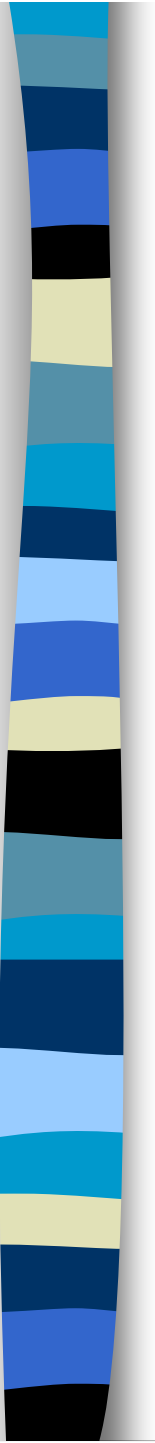
Person with **Dementia**

Person with Dementia



Important Components of Person-Directed Dementia Care

- o Meet the Person's Core Psychological Needs
- o Recognize all Behavior is Meaningful Communication
- o KNOW the PEOPLE with Dementia
- o Teach Staff to Have Fun, be Emotionally Available
- o Change the Language of Care
- o Changing Care Planning – Involve Everyone



Person-Directed Care and People with Dementia

- May be difficult to understand and know what a person with dementia is communicating, choosing or deciding.
- Need to begin by learning about dementia, the person and how to discover needs, wants, desires.

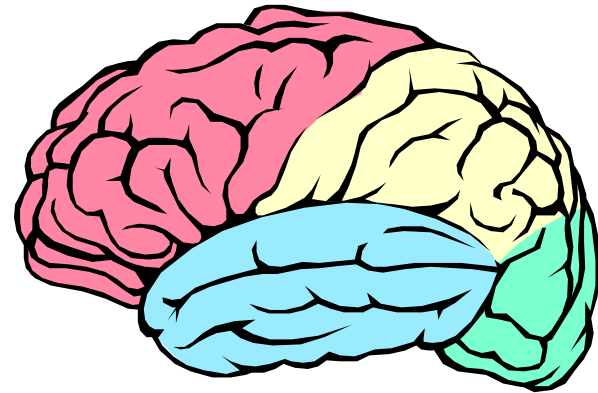


Understanding Dementia

- **How the Brain Works**
 - Ingrained vs. “Holographic” Memory
 - Changing Our Minds to Understand Alzheimer’s disease and related Dementia
 - Aiming the Brain for Success - LANGUAGE

Key Concept: How the Brain Works

- Meet Joe!



- The Great Grape Debate...



Part B - How to Succeed: Caregiving Strategies That Provide Answers for Common Behavior Themes

Behavior	Parenting Approach <i>"Behavior is Exploration"</i>	Alzheimer's Disease Caregiving Approach <i>"Behavior is Communication"</i>	Rationale
Confusion	<u>Correction:</u> Parents correct children who are confused in an effort to help them learn about the environment and what "reality" is.	<u>Enter Their World:</u> The key to solving confusion is to help people with dementia feel safe & listened to, and find something familiar for them to anchor to. <ul style="list-style-type: none"> - Reassure them. Acknowledge what they are expressing – even if it's about a time in their past. Help them to name what they are feeling. - When you find out what is confusing from their point of view, validate their feelings and then help them solve the confusion. - Switch the person with AD from asking about people he is missing from the past, to reminiscing about the people the way the person with AD remembers (the needed connection the person is really asking for). - Direct the person to something familiar to anchor them - a routine, a song, a touch, a favorite activity. (Try to trigger fond memories or "positive holograms.") - In over-stimulation, simplify the situation, eliminate distractions and commotion, slow pace of environment. 	<ul style="list-style-type: none"> - The person with Alzheimer's disease (AD) cannot always perceive our "reality" because his brain can't retain information about the present in the usual ways that it did in the past. - What the person remembers from the past has largely become his present. - Things from the past are familiar and comforting to discuss, remember and do. Connecting with the past is a way of reassuring safety and familiarity in a confusing world. - It is very important to honor the person's memory without correcting it (as in assuming a parent is still alive) – you could risk re-traumatizing the person by reminding him of a past traumatic event. Correcting will not make him remember the truth about the past. He will likely forget a correction in a few moments. - Confusion can also result from forgetting steps in doing a task, feeling overwhelmed by the number of things going on in the environment, or simple inability to recognize anything as familiar.

The Core Psychological Needs of Persons with Dementia





Old vs. New : How do we start?

■ Behavior in “old” language

- Agitation
- Rummaging or “Shopping”
- Wandering
- Egress or Elopement
- Refusing Personal Care
- Repetitive Crying Out

■ New language for behavior

- Energetic/Assertive
- Seeking
- Exploring
- Assertive/Focused/
Showing Initiative
- Cautious
- Assertive



Language Changes Your Perceptions

Starting Point (Old Culture)

- Control
- Problem Behavior
- React
- Correct
- Expect
- "Victim"
- "Pacer"
- Anxiety
- Wandering

Destination (New Culture)

- Accommodate
- Characteristic
- Respond
- Connect
- Accept
- Individual
- Motivated
- Eagerness
- Exploring



New Words for Old Labels

- Agitation – Focused, Determined
- Rummaging - Rearranging security, seeking familiarity
- Elopement – On a mission, Focused
- Refuses Personal Care – Self-sufficient, Modest, Assertive, Protecting self from perceived threat
- Wandering – Seeking, Exploring
- Repetitive Crying Out – Assertive, Asserting for resolution of unmet needs.



Putting it all together

- Understanding Dementia
- Knowing the **Person**
- Meeting Core Needs
- Changing our Environment
- Changing our Language
- Changing our Care Plan



Environment

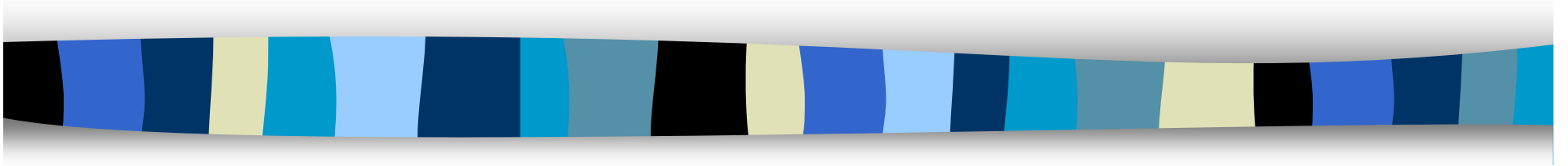
- Familiar as possible to person's home
- Use cues to help with way-finding and independence
- Flexible schedule (wake, sleep, eat,)
- Personalized (Shadow boxes, favorite things)
- Color – large psychological effect
- Activities they can initiate “discovery stations”



Activities

- Every engagement with an individual is an opportunity for an activity.
- Focus is on the **quality of the interaction**.
- Staff utilize list of favorite things and social history to devise special opportunities for people based on their delights and interests.
- Four basic social/emotional needs guide every activity.
- Clubs can be extremely successful.
- The “power of the invitation”.

Video



Rekindling the Spark of Life Clubs

Dementia Care Australia



Team Work

- Everyone must KNOW the people with dementia.
- Anyone can be a leader.
- Involves all departments and staff.
- Regular meeting times, use Learning Circles to problem solve.
- Must have the right staff – love people with dementia.



■ **Quality of Life Outcomes for Persons with Dementia**



As a person with dementia,

1. I have the best possible physical well being.
2. I have meaningful relationships.
3. I have hope because my future is valued and supported.
4. I am accepted and understood as an individual.
5. I am involved in life.



As a person with dementia, I have the best possible physical well being

- I am well hydrated
- I am well nourished
- I am comfortable – free from pain
- I am physically active
- I am clean
- I am safe
- My medical needs are being treated by people knowledgeable in dementia
- I receive the least restrictive intervention for my behavior symptoms



As a person with dementia, I have meaningful relationships

- **I am supported in maintaining ongoing relationships as desired and**
- **I am provided with opportunities to develop new relationships as desired**
- **I have the opportunity to maintain an intimate relationship with my spouse/partner as desired within my capacity**



As a person with dementia, I have hope because my future is valued and supported

- I participate to my capacity in all decisions effecting my life
- I am useful and make contributions of value
- I plan and do things I've wanted to do while I still can
- I have the emotional support and encouragement that I need
- I have positive things to look forward to and do
- I have a legally supported plan for my future needs and wishes
- My previous wishes are honored as my capacity diminishes
- I continue practices that nourish me spiritually



As a person with dementia, I am accepted and understood as an individual

- I am treated as a person not a disease, and am acknowledged as “present”
- I am cared for by people who understand me, and about my dementia
- I have regular opportunities to access and share my rich & meaningful past
- I practice rituals that comfort or calm me
- I continue my own cultural lifestyle
- My orientation to time and reality is respected and supported
- I continue my familiar routines
- My environment is anchored in things I value that are familiar to me
- I have continuity in relationships with caregivers
- I have physical privacy
- My sexual identity is treated with respect
- I am free from all forms of abuse



As a person with dementia, I am involved in life

- I engage in activities that are meaningful to me daily
- I have the opportunity to participate in the life of my community
- I am able to communicate with others to my highest capacity
- I am able to do things independently with safe supports
- I enjoy the tastes, smells, sounds, and feelings of the real world
- I have the opportunity to enjoy/be outdoors



Conclusion

- Would you create a system like we have if you thought that

You were actually going to live here?